



Research priorities by parents of preemies and clinicians who care for them (POP!)

Research priorities of parents of premature babies and Neonatal Intensive Care (NICU) clinicians
San Francisco, CA

Beginning in January 2018, the Parent Clinician Advisory Boards (PCABs) of the California Preterm Birth Initiative (PTBi-CA) in San Francisco, Oakland, and Fresno convened to create priorities for postnatal researchers. The PCABs are made up of researchers, parents of premature infants, and front-line Neonatal Intensive Care Unit (NICU) clinicians from several disciplines (medicine, nursing, respiratory therapy, social work). Priority setting happened over 2-3 meetings at each site and consensus on the top priority topics was achieved at the 2018 all-site meeting. The San Francisco-specific priority research topics, priority research questions, and full list of researchable questions, sorted by topic, are shown below.

We call for researchers, healthcare providers, and health systems to work together to answer these questions - and to share and implement best evidence-based practices – for the health of parents, babies and families everywhere.

Top 10 Topics

1. Development and developmental outcomes/sensory processing
2. Nutrition
3. Pain
4. Parent-infant bonding/skin-to-skin care (kangaroo care; KC)
5. Communication/Consistency around care practices
6. Parent and family experience/social support
7. Prematurity and birth defects
8. Reflux
9. Respiratory disease
10. Developmental follow-up clinics and practices

Top 10 Questions

1. Why are preterm babies at increased risk for autism, ADD, and executive dysfunction?
2. How can we promote healthy lung development?
3. How does early intervention improve outcomes? Such as feeding therapy, OT/PT, home visiting, early childhood intervention?

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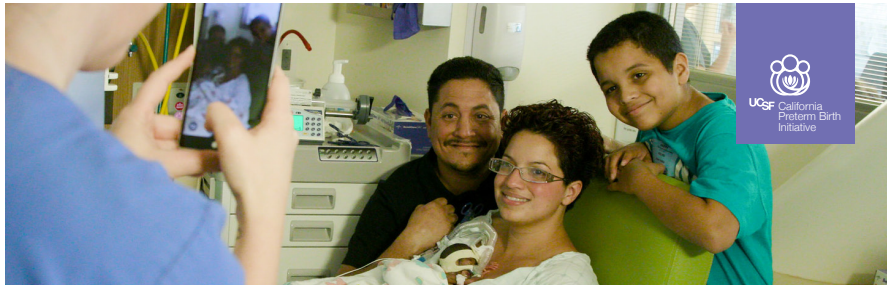
4. How does NICU environment affect development of sensation (i.e. noise/lights) and predispose to sensory processing disorders? Can modifications in the NICU environment prevent sensory processing disorders and improve long-term sensory outcomes?
5. What are the effects of formula, breastmilk, and donor milk on the microbiome, especially in the first weeks of life? How does that affect outcomes?
6. Effect of high caloric intake during NICU stay and early infancy on long-term growth and development into adulthood? Is there a relationship between supplementation and obesity/metabolic syndrome, epigenetics, programming?
7. What are the most effective non-pharmacologic and pharmacologic treatments for reflux in preterm babies? What are the side effects of pharmacologic treatment for reflux in preterm babies i.e. PPIs on kidneys?
8. What is the effect of early pain exposure in preterm infants and long-term pain tolerance?
9. How can the NICU team better communicate to parents the plan of care, long-term goals and what to expect during the NICU journey and beyond?
10. What are the effects of KC on babies and parents? Is KC associated with improved long-term parent/infant bonding?

Researchable questions by topic – San Francisco parents of premature babies and NICU clinicians

Development and developmental outcomes/ Sensory processing

- How to increase awareness of developmental care among nurses?
- Does nursing certification in developmental care change infant outcomes?
- How does gestational age at birth impact different domains of development?
- Why are preterm babies at increased risk for autism, ADD, and executive dysfunction?
- How early can developmental disability be diagnosed?
- How does early intervention improve outcomes? Such as feeding therapy, OT/PT, home visiting, early childhood intervention?
- Does newborn growth and development differ when preemie has comorbid conditions? Differ by body system affected?
- How does radiation (from medical imaging) affect the sensory processing of pre-term infants with birth defects/anomalies?
- Why do preemies have abnormal sensory processing?
- How does NICU environment affect development of sensation (i.e. noise/lights) and predispose to sensory processing disorders? Can modifications in the NICU environment prevent sensory processing disorders and improve long-term sensory outcomes?
- How can we diagnose sensory processing disorders?

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- What are the most effective treatments for sensory processing disorders in preemies?
- How do sensory processing disorders impact parents and parenting? And sibling/families?
- For pre-term infants with birth defects/anomalies how does radiation effect their sensory processing?

Nutrition

- What are the nutritional differences between breastmilk and formula? Do breastmilk and formula have differential effects on infant growth and development?
- How to support moms choice in feeding?
- How to help parents accomplish goals in feeding?
- Are breastfeeding groups effective in improving breastfeeding in preterm infants in the nursery?
- Effect of high caloric intake or fortification/supplementation on long-term growth and development into adulthood? Is there a relationship between supplementation and obesity/metabolic syndrome, epigenetics, programming?
- Growth charts for preemies – are there different growth patterns based on gestational age/birth weight
- Why stop correcting for physical growth and prematurity at 2 years?
- How can we better support parents managing the feeding regimen? What are the resources available?
- What is the Impact of feeding difficulty on parent stress and coping in the nursery and after discharge?
- What is the relationship between feeding and constipation?
- What can be done to improve the nutrition of pre-term infants with birth defects or anomalies?
- How can we better support the nutrition of former pre-term babies?
- What are the effects of formula, breastmilk, and donor milk on the microbiome, especially in the first weeks of life? How does that affect outcomes?

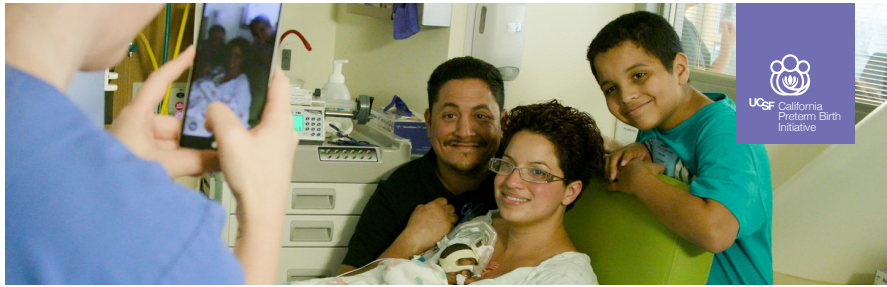
Pain

- How do you measure pain in a preemie?
- What is the effect of early pain exposure in preterm infants and long-term pain tolerance?
- What are the long-term effects of pain and pain medication on babies?
- What are different treatment options for pain?
- Does early narcotic exposure translate into risk of opiate addiction?
- How does GA impact pain tolerance independent of early narcotic exposure?

Kangaroo Care (KC)/Skin-to-skin/ Parent-infant bonding

- How long is it safe to perform KC?
- What are the effects of KC on babies and parents? Is KC associated with improved long-term parent/infant bonding?

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- How does KC impact sleeping behaviors in the nursery, and throughout childhood?
- Does it matter who does skin-to-skin? Mom? Father? Other family members? Non-family members? Hospital volunteers?
- What helps with long-term bonding?
- What can nurses do to help promote long-term bonding?

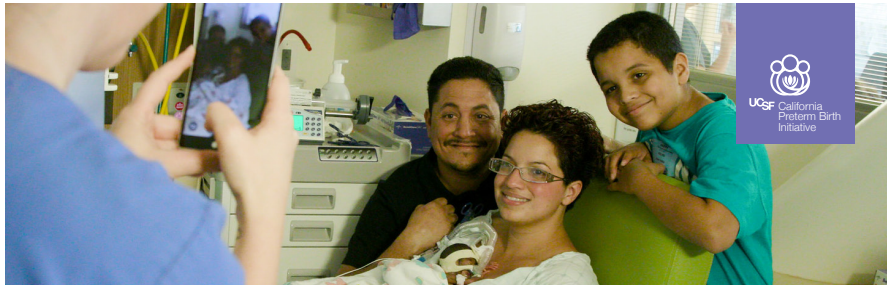
Communication/Consistency around care practices

- How do we deliver anticipatory guidance in the nursery regarding both the short-term and big picture? Who? When?
- Does communication of a specific plan for the week decrease parental stress and uncertainty?
- How do you best communicate medical history from provider to provider throughout the newborns ICN stay and beyond?
- How do you create a solid communication tool from all data in the EMR?
- How do nurses get the best information and communicate it to parents?
- How to promote consistency at the RN level for care practices like flushes and feed rates?
- How are developmental care policies in the ICN implemented and disseminated?
- How can the NICU team better communicate to parents the plan of care, long-term goals and what to expect during the NICU journey and beyond?

Parent and Family experience/Social support

- How do we promote long-term peer support?
- How can we develop community amongst parents?
- What are the effects of social media connections for ICN parents?
- How do parent experiences vary by parental role?
- How parent experience affect long-term coping?
- What supports are there to help parents with various coping experiences?
- How do you support parents in the NICU with limited control and different nurses?
- How can we better support siblings of preemies (physical, emotional, social)?
- How does being a single parent impact day-to-day care in the nursery and after discharge?
- What is the relationship between having a preterm baby and divorce?
- Which interventions/support can be implemented to improve/strengthen parent relationships?
- What are the barriers to family presence in the ICN? How do we address these barriers and support families?
- How can we support/prepare/educate parents about what their baby is experiencing?
- How can we get parents involved in bedside care?
- How does the family SES impact a preterm newborn's developmental outcomes?
- Are there disparities in parent experience?

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Reflux

- What causes reflux in preterm babies and how can reflux be prevented?
- How does reflux differ in preterm babies compared to term babies?
- What is the impact of reflux on parent stress and concern for safety?
- What are the most effective non-pharmacologic and pharmacologic treatments for reflux in preterm babies? What are the side effects of pharmacologic treatment for reflux in preterm babies i.e. PPIs on kidneys?
- How does reflux impact growth?

Respiratory Disease

- How can chronic lung disease be prevented?
- How can we promote healthy lung development?

Developmental follow-up clinics and practices

- Ways to improve developmental follow-up and surveillance for developmental delay outside of the routine visits with PCP and HRIF? (Also life clinic)
- How to decrease parental stress at follow-up visits?
- How can the utility of the time parents have with the provider be improved?
- Are there ways to support parents that are busy looking after their child in clinic?
- Any pre-testing or questionnaires that can be distributed beforehand to make the visit more efficiency?
- What resources can be provided to parents before the visit and after?
- How can the Centering Pregnancy model be adapted to care for preterm babies in the ICN and after discharge? What are the benefits of centering on parents and their babies?

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